

### STATE OF HAWAII DEPARTMENT OF HEALTH

P. O. BOX 3378 HONOLULU, HI 96801-3378 In reply, please refer to:

## NEUROTRAUMA ADVISORY BOARD (NTAB) MEETING MINUTES February 27, 2014

Present: Lyna Burian, Angie Enoka, Elzy Kaina, Scott Sagum, Stella Wong

Excused: Sally Jones, Ian Mattoch, Karen Seth, Milton Takara

Others: Violet Horvath, Pacific Basin Rehabilitation Research Training Center,

(PBRRTC), Hawaii Neurotrauma Registry (HNTR); Val Yamada, Hawaii Neurotrauma Registry (HNTR), Hui Malama Po'o; Kevin Furutani, HNTR

DOH Staff: Curtis Inouye, Michele Tong

- I. Call to Order Meeting was called to order by Stella Wong at 2:00 p.m. Quorum present.
- II. Approval of Minutes from the December 12, 2013 NTAB Meeting NTAB Member Elzy Kaina made a motion to approve the Minutes as written. Motion was second by NTAB Member Angie Enoka. Motion carried to approve Minutes as written by all Board members.
- III. Review of Agenda Ms. Wong reviewed the Board's Agenda. An amendment to the NTAB Meeting Agenda as requested by Ms. Wong to include under: V. Old Business; Hawaiian Islands Regional Stroke network Update. All NTAB Members in agreement to add amendment to the Agenda. Agenda amended.

#### IV. New Business

A. 2014 Legislative Bills:

SB2854 SD1 Relating to the Neurotrauma Advisory Board. SB2854 SD1: On 2/20/14, the Committee on Ways and Means recommended that the measure be passed, unamended. The Bill revises the total number of members of the Neurotrauma Advisory Board from 21 to at least 11 members while still maintaining representation of nearly all existing parties. Recommended for Third Reading.

SB1227 SD2: Relating to health coverage for brain injuries. Requires certain insurance contracts and plans to provide coverage beginning 1/1/2015 for treatment of brain injuries, including cognitive and neurocognitive therapy, neurobehavioral and neuropsychological testing or treatment, and necessary postacute transition services or community reintegration activities for a period of at

least twenty years from the date of injury occurred and up to a lifetime cap per person of \$300,000. Requires auditor to conduct an economic impact study. On 2/26/14, the committee on Ways and Means recommended that the measure be passed with amendments. Recommended for Third Reading.

SB3009: Relating to mopeds; Increases the minimum age to eighteen years to drive a moped. Requires a moped driver of any age to wear a safety helmet securely fastened with a chin strap. No hearing scheduled for this Bill during this legislative session.

HB2304 HD1: Relating to the Neurotrauma Advisory Board. On 2/24/14, the Committee on Consumer Protection and Commerce recommended that the measure be passed with amendments. The bill revises the total number of Neurotrauma Advisory Board members from 21 to 11 members while maintaining representation of all existing parties to facilitate making quorum on a regular basis. Recommended for Third Reading.

HB124: Relating to skateboards, prohibits anyone under \_\_\_\_years of age from operating a skateboard in a public park unless the person is wearing a properly fitted and fastened helmet that meets specified standards. No hearing was scheduled for this Bill during this legislative session.

HB2418: Relating to mopeds, requires moped operators of all ages to wear a helmet and requires mopeds to be insured for personal injury protection. No hearing was scheduled for this bill during this legislative session.

HB1105: relating to transportation, requires applications for moped, motorcycle, and motor scooter licenses to include information on planned safety helmet usage. No hearing was scheduled for this bill during this legislative session.

#### B. Sub-Committee on Educational Initiatives

DOH staff Michele Tong informed Board Members that the Department has set aside funds to begin planning for a future educational initiative on Neurotrauma. Michele informed Board Members that a sub-committee consisting of members from the NTAB as well as Members from the State Traumatic Brain Injury Advisory Board must be established for planning purposes for this initiative. Possible topics for the Initiative were presented by Michele to Board Members for discussion. NTAB Members interested in being a part of the sub-committee can contact DOH staff. Michele will also be present at the next STBIAB Meeting to discuss the planning for the Educational Initiative. The handout on possible topics discussed for the initiative is attached to the Minutes.

#### V. Old Business

A. Hawaiian Islands Regional Stroke Network Update:

The current spoke sites for the regional stroke network are Molokai General Hospital, Wahiawa General Hospital and Hilo Medical Center. Emergency Department M.D.'s and nurses, hospitalists, and administration in these hospitals have been educated on stroke care and paths and protocols and in-serviced on use of the technology. There were a total of 33 telestroke calls completed: 7 from Molokai General; 23 from Wahiawa General; and 3 from Hilo Medical Center.

Refer to the Hawaiian Islands Regional Stroke Network Update which is attached to the Minutes for additional information on the current spoke sites, community education, professional education and potential spoke sites.

#### B. PBRRTC-HNTR Update;

Violet Horvath, Director, PBRRTC-HNTR provided an update on the Hawaii Neurotrauma registry. Violet reported that there are three candidates for the HNTR Advisory Board at this time. HNTR is looking for someone from the employment sector as a possible member.

There are 37 participants in the registry as of February, 2014.

Dylan Arrieta, HNTR Project Assistant completed collecting background information on all State and Federal registries. Violet reported that Hawaii is the only State that works directly with individuals in obtaining information as compared to other States that utilize patient files and death certificates. Dylan's next objective is to obtain additional set of information from all States via phone contact.

Violet reported that their media campaign is going well. The PBRRTC Website is up and running. Dylan will be working on developing a separate page on the website dedicated to the Neurotrauma Registry. Violet also reported that the special edition of the PBRRTC Newsletter came out in February, 2014 in recognition of March as Brain Injury Awareness Month. Beginning in April, 2014, there will be a separate newsletter dedicated to the HNTR which will focus on resources for individuals with neurotrauma injuries. The new issue of Generations Magazine just published contains an article written by Violet which provides information on the HNTR. In the future, information on the HNTR will also be included as articles in the Hawaii Medical Journal and with Hawaii Medical Services Association (HMSA) Magazine-Island Scene. Anyone wishing to have neurotrauma related information be included in PBRRTC's website or newsletter, please contact Violet.

Violet reported that the Neurotrauma intake form has been revised and has gone for review. No problems anticipated.

Presentations and events on the HNTR are ongoing. The latest presentations and events were held at Kapiolani Medical Center for Women and Children for 26 professionals and medical staff and at Castle Medical Center Pacific Neuroscience Institute with Dr. Kore Liow and staff.

Refer to Violet's report which is attached to the Minutes for the PBRRTC website address and additional information on the Hawaii Neurotrauma Registry update.

#### C. Neighbor Island Activities:

Kauai:

Board Member Scott Sagum reported that he is continuing with his Surfer's Myelopathy education and awareness with surf instructors throughout the island. Scott and his team have reached out to 35 surf instructors out of 125 surf instructors that he estimates are on the island. Scott also mentioned that they had provided their curriculum on Surfer's Myelopathy to a large surf school which had roughly 17 instructors, probably the largest surf school on Kauai. The reception at the school went well and the instructors were appreciative of the information Scott and his team provided.

#### D. NT Special Fund Balance –

Current balance in the Neurotrauma Special Fund as of 2/2014 is \$403,352.24. Projected contract encumbrance for Fiscal year 2014 includes \$250,000 for HNTR. Projected Purchase Order claims for Fiscal Year 2014 include website maintenance, Hawaii Health Information Corporation data for Neurotrauma, travel and the Neurotrauma Summer Institute which totals \$92,500

#### VI. Announcements

#### 1. SUPPORT GROUP MEETING

(In collaboration w/Hui Malama Po'o, formerly Hoo'ikaika)

DATE: Saturday, March 1, 2014

TIME: 1:00 - 3:00 pm

PLACE: Rehab Hospital of the Pacific

Wo Conference Rm. #4

TOPIC: Update on Legislative Issues

#### 2. EDUCATIONAL MEETING/PANEL DISCUSSION

DATE: Wednesday, March 12, 2014

TIME: 6:00 - 8:00 pm

PLACE: Rehab Hospital of the Pacific

Wo Conference Rm. #4

TOPIC: Why is Cognitive Rehabilitation So Important PANEL Physicians & Survivors of Brain Injuries

#### 3. SUPPORT GROUP MEETING:

DATE: March 19, 2014 TIME: 6:00 - 7:30 pm

PLACE: Rehab Hospital of the Pacific

Wo Conference Rm. #4

Hope you can all join us at any or all of the meetings. Please note that we are still holding our meetings at Rehab Hospital at the usual times. For any questions, please call me at 521-7721, Lyna Burian. Thanks.

#### VII. Next Meeting

Date: April 24, 2014 Time: 1:30-4:00 pm

Place: Kalanimoku & Neighbor Island VCCs

Adjourned: 3:25 p.m.



# Hawai'i Neurotrauma Registry Update to Neurotrauma Advisory Board February 27, 2014

#### 1. Goal I: Develop and administer a voluntary NT Registry.

The Hawai'i Neurotrauma Registry will assist the Department of Health in prioritizing activities to support the needs of neurotrauma survivors. The Hawai'i Neurotrauma Registry Project, hereafter referred to as "the project," complements the Hawai'i Department of Health, Healthy Hawai'i Initiative in areas of research, public and professional education, and evaluation. The Hawai'i Neurotrauma Registry shall include individuals who have sustained traumatic brain injury, stroke, or spinal cord injury.

The Project Coordinator contacted three (3) individuals who decided to participate in the Registry. One (1) individual who found out about the Registry at the September 2013 Senior Fair just completed a survey online. We just obtained consent for one (1) paper survey that was filled out almost a year ago. All data have been entered into the electronic database. Please refer to Table 1 below.

Table 1: Monthly Update of Participants
Last Update: February 27, 2014

Month & Year	Paper Copy only	Online Only	Both Paper Copy and Online	Total Number of Unique Participants
April 2013	4	n/a	3	7
May 2013	9	n/a	5	14
June 2013	9	7	5	21
July 2013	9	9	5	23
August 2013	9	9	5	23
September 2013	9	13	5	27
October 2013	9	14	5	28
November 2013	9	17	5	31
December 2013	9	17	5	31
January 2014	9	17	5	31
February 2014	10	22	5	37

#### a. Advisory Board of Stakeholders

There are three (3) candidates for the HNTR Advisory Board at this time:

- 1. Curtis Inouye, DOH—DDD, Outcomes and Compliance Branch, is already committed.
- 2. The Project Director is awaiting approval from Dr. David Fray regarding her invitation to Jenny Gong at Department of Health, Developmental Disabilities.
- 3. The Project Coordinator sent an inquiry to Sherry Lauer, the former Pediatric Trauma Coordinator at Kapi'olani Medical Center and currently the State Trauma Program Coordinator for Emergency Medical Services & Injury Prevention System Branch. Ms. Lauer responded she would welcome the opportunity. Dr. Horvath will send an official invitation.

The Project Coordinator also sent an inquiry to the Office Manager at O'ahu WorkLinks to find a representative from organizations assisting with employment. The request was forwarded to the Disability Employment Initiative Project as they may be interested in registry data. The Project Coordinator will follow up. See the link below for more information on the project: <a href="https://disability.workforce3one.org/page/tag/dei\_project">https://disability.workforce3one.org/page/tag/dei\_project</a>

#### b. Research Best Practices for Nationwide Neurotrauma Registries

The Project Assistant completed research on Federal and State registries. We are in the process of developing questions to ask about States about their best practices associated with their registries.

c. Develop a Comprehensive Implementation Plan for Statewide Recruitment

Staff will meet shortly to discuss the progress over the past eleven (11) months of HNTR development and implementation, and develop a prioritized plan for the next 13 months.

Staff continues community outreach for recruitment. The Project Coordinator continues to arrange presentations to professional organizations and exhibitor's tables at community events not only to publicize the existence of the registry but to recruit for participants.

#### i. Establish Network of HNTR Partners and Collaborators

The recruitment plan includes networking with other organizations and individuals to promote the Registry and inform and educate others about neurotrauma injuries. The Project coordinator arranged presentations to service providers and exhibits at community eventshas intitiated collaborations with the following organizations:

 January 7, 2014: Queen's Medical Center (QMC)/JABSOM Trauma Board presentation. The Project Director and the Project Assistant informed four (4) members of this board about the registry and dispersed 18 brochures. The Project Director was also able to visit Dr. Alan Stein, Medical Director for Epilepsy and Neurophysiology at QMC. Cora Speck of QMC's Injury Prevention Program offered to speak with the new medical director about further opportunities to promote the registry.

 January 14, 2014: Kapi'olani Medical Center presentation. The Project Coordinator introduced the registry to 26 medical and health service professionals at the Kapi'olani Medical Center for Women and Children. The Project Director attended to network with attendees who were interested in knowing more about the registry. The Project Assistant helped with dispersing materials and promotional items.

Attendees were interested in the broad range of participants, from infants with Shaken Baby Syndrome or other neurotrauma injuries to toddlers, teens, adults, and the elderly. There were questions about the benefits of participating in the registry as well as benefits to those who referred potential participants to the registry. Laura Bonilla, the organizer of KIDSFEST, mentioned that she would refer other organizations for a presentation. Dr. Devin Puapong, medical director of the Pediatric Trauma Program suggested HNTR introduce the registry to the Hawai'i Trauma Advisory Council, an advisory group to DOH.

• February 5, 2014: Hawai'i Pacific Neuroscience Institute (HPNI) presentation. The Project Director introduced the registry to Dr. Kore Liow, two physicians on staff, an intern, and several staff members during HPNI's Weekly Neruroscience Grand rounds. As these sessions occur during the lunch period, physicians and staff were not able to attend continuously except for Dr. Liow. He expressed an interest in establishing a collaboration between HPNI's stroke and brain injury clinics and the project with the project providing information and referral to patients attending these clinics. The project prepared 100 brochures, 50 of which were requested by Dr. Robert Sloan.

Dr. Michiko Inaba invited the project to participate in a longterm health fair conference at the Hale Koa Hotel on October 14, 2014. The audience is diverse, including nursing home physicians, social workers, nurses, therapists, and nursing home administrators. Dr. Inaba forwarded the Project Director's contact information to the organizers.

 Results of Contacts from Kupuna Safety Fair, January 23, 2014 (please refer to d.ii below for details of this community outreach event): 'Ewa Beach Weed & Seed and the Boys and Girls Club of Hawai'i:

The result is that the Project Coordinator will develop a TBI presentation, appropriate for school-aged children seven (7) to 12 years old, to be delivered during Spring Break in March 2014. The presentation will include information on concussions and interactive videos and games. The Project Assistant will present and facilitate an activity—students will first race raw eggs wrapped in cellophane on spoons. Working in groups, they will then devise "helmets" made of bubble wrap and other materials to protect the raw eggs. They will then race again with the eggs wrapped in their protective "helmets."

Following HNTR's presentation and activities, a representative from ThinkFirst will present on being "street smart" to prevent injuries. The Project Coordinator, Project Assistant, and ThinkFirst representative met on February 24, 2014, to plan for the event, scheduled for March 20, 2014.

- 'Ewa Beach Disaster Preparedness Committee: The result was an invitation to the Get Ready 'Ewa Beach event on September 6, 2014.
- CHIMACE (chi-mah-say) [Child Massage Center]: CHIMACE is a 501 (c)3 organization that promotes healing through massage, training, and education for children and their parents. Zorka Pinkas, the Executive Director, invited HNTR to participate in the CHIMACE Keiki Health Fair at Bishop Museum on March 8, 2014. CHIMACE is also promoting HNTR through its fliers and radio PSAs for this event. This Keiki Health Fair is expected to draw 500 attendees. The Project Coordinator and one (1) project volunteer will manage an exhibitor's table with project information and memory-building games for children and their families.

#### ii. Community Outreach

- January 17, 2014, Orientation
  - a. Five (5) individuals attended
  - b. Three (3) submitted applications to become project volunteers
- January 23, 2014, Kupuna Safety Fair. See **d.ii.**, Volunteer Involvement in Community Outreach and Recruitment, below for details.

#### d. Development a Volunteer Program

- HNTR will proceed with FBI and State Criminal History background checks for volunteers. Staff is still developing a procedure for payment and scheduling for these background checks.
- HNTR had its first recognition event on December 14, 2013, at the Old Spaghetti Factory. Fourteen (14) guests, including project volunteers, HNTR advocates, and several members of the advisory boards (Elzy Kaina, Bill Rodrigues, Dr. Robert Sloan, and Angie Enoka) attended. Dr. Satoru Izutsu, HNTR Principal Investigator, Roxanna Bolden, Executive Director of Aloha Independent Living Hawai'i, a HNTR collaborator, and Dr. David Fray from the Department of Health, Developmental Disabilities Division, Outcomes & Compliance Branch, also stopped by.

#### i. Develop Volunteer Training

#### Completed:

On January 18, 2014, the Project Coordinator and Project Assistant conducted a pilot of the "What Are Neurotrauma Injuries?" training. Eight (8) volunteers attended and provided feedback. Based on their recommendations, the Project Coordinator will add content and interactivity to the three sections—Brain Injury, Stroke, and Spinal Cord Injury—and separate one long presentation into three shorter ones. The Project Coordinator will revise the content of these trainings, and the Project Assistant will help with video embedding, animation, and other media utilization. There will be one neurotrauma injury training per month to determine whether further revision will be necessary.

Evaluations indicated that all participants responded positively with "agree" or "strongly agree" to all items. No one had negative comments.

#### Future:

February 28, 2014, "How to Promote HNTR" Training

The Project Coordinator has completed a draft of the curriculum for a volunteer training on how to interact with a variety of people during community outreach. The training is interactive. The Project Coordinator will facilitate Part I as volunteers identify what they already know about the Registry through orientation, interaction with staff, or the PBRRTC newsletter and organize this content into an easily referenced cheat sheet. Part I will identify gaps in knowledge as well. In Part II, the Project Assistant will role play various types of people who may pass by or visit the HNTR exhibitor's table. Volunteers will practice speaking about the Registry. Part II includes a mock up of the display table where volunteers practice dispersing project materials and playing memory building games while talking about HNTR.

#### ii. Volunteer Involvement in Community Outreach and Recruitment

The following efforts in community outreach and recruitment involved volunteers:

- On January 23, 2014, the Project Coordinator, Project Assistant and two (2) volunteers managed an exhibitor's table during the first annual Kupuna Safety Fair, organized by the 'Ewa Beach Weed & Seed program.
  - Established person-to-person with 114 seniors
    - Played memory-building games using die, cards
    - Tested NT knowledge with T/F questionnaire on TBI, stroke, and spinal cord injury
  - Dispersed 83 HNTR brochures
  - Distributed 71 Aloha Independent Living Hawai'l brochures (HNTR collaborative organization)

#### e. Provide and Document Information and Referral

The Project Coodinator continues to provide and maintain documentation of contacts to the project and information and referral for these contacts. Table 2 below includes the date of contact, name of individual or organization, and the result of the contact from the time of the last meeting until now.

**Table 2: Information and Referral Ongoing** 

Date	Contact	Result of Contact
02/21/14	Hui Malama Poʻo Chair for BIA— HI Facilitator	Provided name and contact for training at National Center on PTSD Honolulu for panel on brain injury for monthly evening meeting 03/19/14
02/20/14	Woman seeking Mini Medical School on Healthy Aging	Provided w/ name and contact at JABSOM
02/20/14	15 Hui Malama Poʻo members	Provided w/ tool for daily use to help self-esteem, confidence, frustration from Catz LeBlanc's Tell Me This: Encouragement & Hope after Brain Injury
02/19/14	Individual w/ TBI	Referred to AILH for help w/ organizing finances
02/10/14	The Caregiver Foundation	Provided referral and flier for Stroke Vendor Fair at Rehab, 05/06/14
02/05/14	Intern at Hawai'i Pacific Neuroscience Institute	Provided HNTR O'ahu Resource Listing as requested
02/03/14	Individual w/ TBI	Needed help with staying in mental health day program at Queen's; referred to HDRC. Wanted to join BIA—HI Resource Center programs for cognitive training; referred to DVR.

02/03/14	Family Member of Person w/	Emailed link to online intake survey; referred to HDRC, Hui, BIA-HI, and DVR
01/31/14	Individual w/ recent TBI	Provided names and contact for 3 lawhers, referred to online site for employment attorneys
01/28/14	Boys & Girls Club of Hawai'i, 'Ewa Beach	Provided w/ HNTR brochure, referral forms
01/28/14	Weed & Seed, Hale Pono, Office Manager	Provided w/ HNTR brochure, referral forms
01/23/14	Volunteer for 'Ewa Beach Emergency Preparedness Committee	Provided w/ HNTR brochure, referral forms, business cards
01/23/14	Caregiver for senior mother	Referred to Aloha Key for medical alert bracelets; emailed PYT for awareness bracelets cost, etc.
01/23/14	Elderly individual w/ TBI	Referred to Elderly Affairs Division for health and sanitation problem
01/16/14	Individual w/ recent TBI	Referred to DCAB regarding a safety issue
01/10/14	Elderly individual w/ TBI	Followed up previous referral to AILH; able to establish contact between individual and AILH staff
01/09/14	Individual w/ PTSD and TBI	Provided information to peer coaching program, reconnected to interrupted AILH services
01/08/14	Elderly individual w/TBI	Wanted help with organizing files, mail, Referred to AILH
01/08/14	EFMP Family Case Worker - MCB Hawai'i	Referred to BIA—HI for mentoring program
01/07/14	Student w/ recent TBI	Referred to HDRC, DVR, NT Helpline, Pacific Neuroscience, AILH, BIA—HI, and Hui Malama Poʻo
01/03/14	Elderly individual w/ TBI, stroke, and SCI	Referred to <i>Generations</i> magazine
01/02/14	Elderly individual w/ TBI	Referred to legislators from appropriate district
01/02/14	Project Manager, National Children's Study, Diet Hawai'i at UH Manoa	Requested resources and TBI information for friend w/TBI; provided w/CDC site, and 7 factsheets regarding concussion, what to do after TBI, related CDC information.
12/27/13	Elderly individual w/ TBI	Provided information to DOH Sanitation

12/26/13	Elderly individual w/ NT injuries	Provided HNTR information
12/19/13	HDRC representative	Referred to BIA—HI,DVR, and Hui Malama Poʻo
12/13/13	R. Jacob Leonesio, M.S., Ph.D., CPT University of Washington (Referred by Stanley J. Michaels Injury Prevention Specialist Hawaii State Department of Health Emergency Medical Services Injury Prevention Systems Branch)	Provided Dr. Leonesia with Intro to HNTR PPT

## 1. Goal 2: Develop and disseminate an effective PSA and social media campaign

Collaborate with Developmental Disabilities Division, State Traumatic Brain Injury Advisory Board, and State Neurotrauma Advisory Board to assist in the development of the PSAs.

- PBRRTC Newsletter: The Project Director and Administrative Program Associate distributed the third, fourth, and fifth editions of the monthly newsletter on December 18, 2013, January 15, 2014, and February 12, 2014. A special edition of the newsletter for March is Brain Injury Awareness Month went out on February 26, 2014.
- The Project Assistant and PBRRTC Program Administrative Associate are working together to develop social media marketing.
- PBRRTC has a website: jabsom.hawaii.edu/pbrrtc. HNTR will have a page on this website.
- The Project Director and Project Assistant will create a quarterly HNTR newsletter that focuses on resources for those with neurotrauma injuries and on HNTR activities.

## 2. Goal 3: Develop and Implement an Evaluation Process to Assess the Goals and Objectives of the Hawai'i Neurotrauma Registry Project

Staff members use participatory and formative evaluations for all project orientations and trainings. Outcomes are included in the semi-annual report.

#### • Evaluate Effectiveness of Project

#### a. Participatory and Formative Evaluation

The Project Coordinator continues to collect participatory and formative evaluation data and uses the information to improve project materials. The Project Assistant is putting these data into a database. Results available for an orientation on January 17, 2014, and a pilot of the "What Are Neurotrauma Injuries?" training on January 18, 2014. See below.

Five (5) persons attended and completed evaluations. The rating scale was:

Strongly agree

- Agree
- Disagree
- Strongly disagree
- NA (not applicable)

Most items were rated "strongly agree" and some were rated "agree." One item was rated "not applicable." There were no "disagree" or "strongly disagree" ratings.

Four (4) participants commented in the "What I liked best about the presentation was..."

- Mari [Project Coordinator/facilitator] is very informative and detailed. She's
  willing to help, listens to any problem, and refer to another resource if she can't
  help.
- Answered all my questions and concerns.
- Food and information
- Very interesting to hear people

Regarding the "What Are Neurotrauma Injuries?" pilot training, eight (8) volunteers attended and five (5) completed evaluations. Nearly the same number of items were rated "strongly agree" or "agree." There were no "disagree," "strongly disagree," or "NA" (not applicable) ratings.

Two participants commented under "What I liked best about the activity was..."

- Interaction between participants good. Separate presentation, little darker letters heading or change color [regarding PPT background and text]
- The mtg was fun and gave breaks when needed, not to[o] long and information understandable, if not Mari takes time out to explain

Based on the comments, the Project Coordinator has reformatted as recommended and separated from one (1) to three (3) separate trainings: One on brain injury, a second on stroke, and a third on spinal cord injury. The Project Coordinator also added content on what a person sustaining a brain injury could expect to experience and recognizing stroke, including different symptoms for women.

#### a. Summative Evaluation

Summative evaluation on the project's progress is provided in the Semi-Annual Report for Period 1, March 21, 2013—September 30, 2013 (first six months of project). Included in the summation are aggregate data on demographics of persons completing the intake surveys and the responses. Also covered are the following for this period:

- Effectivenss of orientations and trainings
- Summation of recruitment efforts
- Efforts needed to address goals and objectives

• The focus is now on the report for the Period 2 for Contract Year 1, October 1, 2013 to March 21, 2014

#### 3. Goal 4: Reporting

- a. Report and Update Project Progress to the Following Organizations
  - i. 4.1.1. Neurotrauma Advisory Board
    - 1. June 21, 2013
    - 2. August 22, 2013
    - 3. December 12, 2013
  - ii. 4.1.2. State Traumatic Brain Injury Advisory Board
    - 1. May 17, 2013
    - 2. July 19, 2013
    - 3. September 27, 2013
    - 4. January 17, 2014
  - iii. 4.1.3. State Department of Health, Developmental Disabilities Division, Outcomes and Compliance Branch
    - 1. June 5, 2013
    - 2. July10, 2013
    - 3. August 7, 2013
    - 4. September 11, 2013
    - 5. October 9, 2013
    - 6. December 11, 2013
    - 7. January 8, 2014
    - 8. February 12, 2014

## b. Objective 2: Health Insurance Portability and Accountability Act of 1966 (HIPAA) Compliance

The Hawai'i Neurotrauma Registry Project staff have completed and received Curriculum Completion Certificates for the following HIPAA trainings:

- Social and Behavioral Research—Basic Refresher Curriculum
- Social and Behavioral Responsible Conduct of Research
- c. Objective 3: Semi Annual Reports to State Department of Health, Including Electronic Data

The Project Director is finalizing the semi-annual report covering Period 1, March 22, 2013—September 22, 201, of Contract Year 1.

- Semi-Annual Period 1: March 22, 2013—September 22, 2013
- Semi-Annual Period 2: September 23, 2013—March 21, 2014
- d. Objective 4: Provide Annual and Final Report to State Department of Health Not applicable at this time.

The annual report covers the first twelve (12) months of progress for the Hawai'i Neurotrauma Registry Project. The final report concludes the Contract. Both reports include documentation to show fulfillment of the Contract. An original and one (1) copy

is submitted to the Hawai'i State Department of Health, Developmental Disabilities Division, Outcomes and Compliance Branch.

#### Federal and State Neurotrauma Registries Highlights

Table 1 FNTR Summary

n	56
TBI	50
Stroke	11
SCI	8
Mandatory	0
Voluntary	2
Coverdell	11
RO	10
R1	5
R2	1.4
R3	10
R4	24
R5	7
R6	6
R7	2
88	1
R9	4
NO.	5
N1	29

#### Reference Guide for Table 1

Reference (	suide for Table 1
R0=Virtual	outreach/webinars
R1=Comm	unity outreach
(parents, s	chools)
R2=Profes	sional outreach
(hospitals,	physicians)
R3=Resour	rce booklets,
brochures	, collaterals
B4=Educat	tion, training,
conference	es, retreats
R5=Brain i	njury networks,
specific or	ganizations
R6=TV/rac	lio media
R7=Needs	and resources
assessmer	it/surveys
R8=Nursin program	g home, Medicaid
R9=Social	media, websites
N0=Has no	ever received a TBI
State Gran	it
N1=Currer	ntly does not have a
Federal TB	I Program
Implemen	tation Partnership
State Gran	t

Table 2 SNTR Summary

n	53
тві	52
Strake	0
SCI	14
Mandatory	9
Voluntary	4
App0	8
App1	1
App2	1
Арр3	2
App4	3
SO SO	13
S1	14
S2	1
\$3	2
S4	2
S5	2

#### Reference Guide for Table 2

App0=Surveillance data are no used to make referrals for	t
services	
App1=For public education,	
grant responses and legislative review	0
App2=Provides lifelong case	
management services	
App3=Resource directory of	
services in the state	
App4=Refer services	
S0=Death certificates/ME	_
reports	
S1=Medical/hospital/discharg records	e
S2=Medicaid data	_
S3-Transportation departmen records	ıt
S4=Rehab records	_
S5=EMS	_

#### Nationwide TBI highlights:

There are 50 states and territories that have some type of TBI registry, task

force, and/or programs implementing the dissemination of TBI-related resources. The most common ways the nation underwent recruitment were through virtual, community and professional outreaches, education and training conferences, and brain injury-related organizations.

#### Statewide TBI highlights:

There are 52 states and territories that have a TBI registry. The most common data source for these registries is medical records, followed by death certificates. Currently, majority of the states do not use this data to make referrals for services.

More research is needed to determine whether or not both nationwide and statewide registries are mandatory or voluntary.

Stroke highlights: There are currently 11 states that have their stroke registries funded through the Coverdell program. These 11 states have participating hospitals that oversee these registries.

SCI highlights: The research so far shows little nationwide and statewide SCI registries. More research is needed to validate their existence.

#### Hawaiian Islands Regional Stroke Network Update

(Funded by a grant from the Hawaii State Dept. of Health Neurotrauma Fund)

Hub site: The Queen's Medical Center

#### Current spoke sites:

Molokai General Hospital, Wahiawa General Hospital and Hilo Medical Center are active. Three spoke site hospitals – ED MDs and nurses, hospitalists, and administration - have been educated on stroke care paths and protocols and inserviced on use of the technology.

- Number of Telehealth sessions:
  - 33 Telestroke calls completed:
  - 7 from Molokai General Hospital (activated on 11/8/2011)
  - 23 from Wahiawa General Hospital (activated on 6/21/2012)
  - 3 from Hilo Medical Center (activated on 8/1/13)
- 6 calls not completed could not connect or complete due to technical reasons.
- Outcomes of calls: 18 of 31 patients transferred to QMC
  - 17 patients received tPA at spoke site and 14 subsequently transferred to QMC.
    - Pt. 1: Initial NIHSS of 9 and discharge NIHSS of 2. D/C to home.
    - Pt. 2: Initial NIHSS of 6 and discharge NIHSS of 1. D/C to home.
    - Pt. 3: Initial NIHSS of 16 and discharge NIHSS of 16. D/C to hospice with left lung small cell carcinoma and metastases to the brain.
    - Pt. 4: Initial NIHSS of 5 and discharge NIHSS of 1. D/C to home.
    - Pt. 5: Initial NIHSS of 14 NIHSS of 0. D/C to home (Question of malingering or conversion disorder).
    - Pt. 6: Initial NIHSS of 13 which did not improve. D/C to nursing home.

Pt. 7: Initial NIHSS of 6. NIHSS of 2 upon arrival to QMC (5/28/13) DC to home.

Pt. 8: Initial NIHSS of 5 decreased to 0 on transfer. DC to home.

Pt. 9: Initial NIHSS of 8. DC to RHOP-hemorrhagic conversion

Pt. 10: Initial NIHSS of 3 and remained with NIHSS of 3 on 6/11/13. DC to home.

Pt. 11: Initial NIHSS of 11. DC to RHOP and last NIHSS was 13.

Pt. 12: Initial NIHSS of 13. Pt not transferred to QMC. DC to home after 3 days in rehab at HMC. Final NIHSS was 0.

Pt 13: Initial NIHSS of 11. Patient with improved movement but remained aphasic after transfer to QMC. DC to RHOP with final NIHSS of 6.

Pt 14: Initial NIHSS 7 at time of Telestroke and 15 on arrival at QMC. DC to RHOP

Pt 15: Initial NIHSS 7. Complete resolution of stroke symptoms after IV tPA administration with NIHSS score of 0 on arrival to QMC. DC to home.

Pt 16: Initial NIHSS 6 and remained at HMC. Transferred to Kaiser on day of service with an NIHSS of 4

Pt 17: Initial NIHSS 7 and remained at HMC. DC to SNF ambulating w/ assist and feeding herself (No NIHSS documented).

- 4 patient did not receive tPA but transferred to QMC for closer monitoring and further evaluation.
- 1 patient transferred to QMC but final diagnosis of seizure
- 11 patients remained at spoke site since they were not tPA candidates and did not require a higher level of care. These patients were found to be either mild stroke, complex migraine, old stroke, ICH or with transient symptoms.
- Telemedicine encounters require 40- 45 minutes of direct critical care time

#### Community Education

- 15 Craigside Place July 22, 2013, educated 100 seniors on "Stroke: What you should know."
- Waipio Senior Fair June 21, 2013, Hawaii Okinawan Center, partnered with Wahiawa General Hospital and Genentech to conduct stroke risk assessments with 240 people and educate on stroke signs and symptoms and telestroke network.
- QMC May 29, 2013, educated 150 medical center staff and guests on the stroke chain of survival (i.e. stroke risk factors, stroke signs and symptoms, acute stroke treatment and the telestroke network).
- Hawaii Dental Services May 16, 2013, educated 40 worksite staff on "Heart Disease and Stroke: What women should know."
- QMC April 24, 2013, educated 15 volunteers on "Stroke: What you should know."
- Moanalua Middle School Health and Safety Fair February 15, 2013, educated over 75 middle schoolers on signs and symptoms of stroke.
- Wahiawa Community Health Fair October 27, 2012, educated over 300 in the Wahiawa community about stroke and signs and symptoms and introduced them to Hawaiian Islands Regional Stroke Network Camera System.
- Article in Star-Advertiser on 10/18/12.
- Home Instead Senior Care presentation September 20, 2012, educated 40 caregivers on "Stroke signs and Symptoms."
- Central Pacific Bank presentation September 26, 2012, 12 noon educated 12 bank staff on "Stroke: What you need to know."
- Article in Star-Advertiser on 3/7/12.
- Farmers' Market display in Kaunakakai, Molokai Nov. 2011.

#### Professional Education

- Big Island Symposium on Cardiac and Stroke Care August 9, 2013, Hapuna Beach Prince Hotel – Matt Koenig, MD, "Evaluation of the patient with a suspected stroke. The role of telemedicine." – Douglas Valenta, MD, "Prevention of Stroke."
- QMC Grand Rounds May 19, 2013 Cherylee Chang, MD, "Treatment for stroke: what's new, what's not, what's out.
- UH Medicine Grand Rounds Feb. 19, 2013, Matt Koenig, MD,
   "Collaborating for Emergency Care of Acute Stroke Patients in Hawaii: Telestroke &Triage"
- Get With the Guidelines Stroke Workshop February 9, 2013 Matt Koenig, MD, "Telestroke: Optimal Use of Telehealth to Improve Stroke Outcomes."
- Wahiawa Grand Rounds Nov. 20, 2012, 1pm, Matt Koenig, MD,
   "Telestroke: Optimal Use of Telehealth to Improve Stroke Outcomes,"
- EMS Advisory Committee Oct. 18, 2012 Pre-Hospital notification
- Big Island Cardiac and Stroke Care Symposium August 10, 2012, 8am-4pm, Hapuna Beach Prince Hotel – Dr. Koenig, "Building a Stroke System of Care" and "Telestroke: Optimal Use of Telehealth to Improve Stroke Outcomes."
- Stroke lectures for EMS: August 9, 2012 Federal Fire, August 16, 2012
   KCC paramedic students. Dr. Cherylee Chang presented.

#### Potential Spoke Sites

- Kauai hospitals Wilcox Medical Center and Kauai Veterans Memorial Hospital are working through how they want to proceed.
- Maui Memorial Medical Center Template of spoke hospital agreement was sent and they are moving forward with reviewing it.
- Big Island hospitals Kona Community Hospital and North Hawaii Community Hospital are now interested. We will plan to do a site visit in September.
- Queen's West will open in Spring of 2014 and will utilize the telestroke camera.